Complex regional pain syndrome acute care pathways in England: Do they exist and what do they look like?

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Abstract

Introduction: Complex Regional Pain Syndrome is a condition with a high degree of morbidity and health costs to the National Health Service (NHS), characterised by persistent pain, sensory, motor, trophic and autonomic signs and symptoms. The British Orthopaedic Association (BOA) and the Royal College of Physicians (RCP) have recommended treatment guidelines and care pathways for the management of acute Complex Regional Pain Syndrome. The objective of this scoping exercise was to use Freedom of Information (FOI) requests to ascertain whether NHS Trusts in England had such pathways and what they looked like.

Methods: FOI requests were sent to 126 English NHS Trusts on 9 March 2017 on behalf of the Complex Regional Pain Syndrome Clinical and Research Network UK, asking: “What does your acute Complex Regional Pain Care Syndrome pathway look like?”

Results: Replies were received by 95 NHS Trusts and of these 84 had relevant services but (82%) had no pathway or agreed initial management.

Conclusions: It appears to be common for no acute care pathway to exist for CRPS in NHS Trusts in England despite it being a domain in BOA national guidelines. The Royal College of Physicians guidelines also recommend integrated MDT care. Consequentially, BOA and Royal College of Physicians standards in acute CRPS management are not yet being followed in most acute NHS Trusts in England providing trauma care. Where there is a pathway agreed, it is rarely integrated and truly multidisciplinary.

Keywords

Trauma, orthopaedics, rheumatology

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Introduction

Complex Regional Pain Syndrome (CRPS) is a highly painful, multifaceted, complex condition characterised by sensory, autonomic, trophic and motor abnormalities: CRPS cannot be attributed exclusively to one system or mechanism.1–3 Bruehl and Cheung described CRPS as a “biopsychosocial disorder” whereby psychological, behavioural, and pathophysiological factors interact in a complex manner.4 It is a condition that typically but not exclusively arises after trauma to distal limbs.

CRPS causes a dramatic decline in the quality of life for those affected and results in exceptionally high costs to society due to health costs and lost working hours.5,6 Although uncommon in the general population with an incidence of 26/100,000 in Europe it can rise following up to 25% of wrist fractures and is a
widely known complication after other fractures and surgery, usually occurring within one month of trauma, surgery or immobilisation.\textsuperscript{7–10} It can occur spontaneously in approximately 9\% cases but even minimal trauma can result in this condition.\textsuperscript{7–10} The course of CRPS is highly variable: in many patients, symptoms improve markedly within 6–13 months; however, many more have longer lasting pain and symptoms.\textsuperscript{11} Longevity of symptoms has been reported in 15–64\% of patients at one to five years post onset with persistent pain and physical impairment.\textsuperscript{11,12} Fifteen percent of patients will have undiminished pain and physical impairment at six years post onset, but an additional 40\% of patients will have some degree of pain, dysfunction and activity limitations.\textsuperscript{11–13}

Although there are no randomised clinical trials confirming that CRPS can be prevented by implementing early appropriate rehabilitation, emerging research suggests incidence and severity of upper limb CRPS after distal radius fracture can in fact be dramatically reduced with simple interventions and where appropriate care pathways have been put in place.\textsuperscript{14,15} Furthermore, longevity and severity of symptoms are thought to be reduced by early appropriate multidisciplinary team (MDT) intervention. Reducing CRPS morbidity is desirable in order to minimise individual suffering, secondary physical problems associated with disuse, psychological consequences of living with chronic pain, and the concomitant exorbitant costs known to be associated with this condition.\textsuperscript{16}

Accordingly in the UK, the British Orthopaedic Association (BOA) and the Royal College of Physicians (RCP) published treatment guidelines and an agreed care pathway for the management of acute CRPS, which emphasise the importance of early identification and initiation of rehabilitative treatment.\textsuperscript{17,18} Adherence to these recommendations has potential individual, organisational, and socio-economic benefits.

The British Orthopaedic Association Standards for Trauma (BOAST) standard 7 point 11 for fracture clinic services states, “Complex Regional Pain Syndrome should be identified early and there should be an agreed protocol for analgesia and therapy with the local pain clinic.”\textsuperscript{17} It is recognised that there will be variation in the configuration of these services across the UK but it is made clear that this is a standard that all patients should expect.

RCP recommends using diagnostic criteria and an integrated interdisciplinary approach using four pillars of intervention\textsuperscript{18}:

\begin{itemize}
  \item[(i)] Physical and vocational rehabilitation
  \item[(ii)] Pain relief (medication and procedures)
  \item[(iii)] Psychological interventions
  \item[(iv)] Patient information and education to support self-management
\end{itemize}

The authors’ own experience in receiving patients referred from other centres suggests that acute CRPS care may often be inconsistent and care pathways fragmented, despite the publication of these guidelines. Local CRPS care pathways are beginning to emerge in publications; however, there is as yet no nationally agreed service specification.\textsuperscript{14,18,19}

This scoping exercise project used Freedom of Information (FOI) requests to ascertain whether NHS Trusts in England have implemented such pathways by the census date March 2017, and to investigate their structures. The Freedom of Information Act, 2000\textsuperscript{20} provides a right of access to a wide range of information held by public authorities in the UK, including the NHS. The purpose is to promote greater openness and accountability. There is a legal obligation to reply to FOI requests within 20 working days of receipt. NHS Trusts in England were targeted for the purposes of this enquiry to ensure the volume of data was manageable; additionally variation in commissioning arrangements throughout other sectors of the UK may have made the results more difficult to analyse.

**Method**

All 126 NHS Trusts in England, identified from the Freedom of Information (FOI) website, were sent a FOI request via email in March 2017 on behalf of the CRPS Clinical and Research Network UK.\textsuperscript{21} The request was addressed to the Trust’s trauma, orthopaedic, rheumatology and hand services (as this is where most acute CRPS patients originate from), via the FOI lead asking: “What does your acute Complex Regional Pain Care Syndrome (CRPS) pathway look like?”

Responses were categorised using a Microsoft Excel Spreadsheet under the following domains:

A) Has relevant service,
  A1). No Acute CRPS guideline/pathway in place
  A2). CRPS care pathway in place
  A3). Pathway in development
  A4). No multidisciplinary pathway, but described access to physiotherapy/occupational therapy (PT/OT)
  A5). Access to pain team
  A6). Access to psychology
  A7). Quoted national guidelines but did not demonstrate a local pathway
  A8). Quoted Budapest criteria but did not demonstrate a local pathway
  A9). Quoted BOAST guidelines but did not demonstrate a local pathway

B) No relevant service
The pre-determined (expected) domains, i.e. pathway/no pathway, evolved to include unexpected categories within the replies to the FOI requests: A3 to A9. Additional comments received from respondents, that fell outside of the above domains were documented.

Results

Of 126 FOI requests sent to NHS Trusts, 95 replies were received (75% response rate). Of these 84 trusts had relevant services: that is acute trauma, orthopaedic, rheumatological or hand services.

Sixty-nine (82%) of the 84 respondents with relevant services stated that they had no existing pathway or agreed initial management procedure in place whilst 15 (18%) stated they had an acute pathway and 3 (3%) stated they had a pathway in development (Figure 1).

Analysis of the responses in more depth were sub-categorised, in terms of missing or present elements with some matching 1 or more subcategories. The sub-categorised responses within category A are illustrated in Table 1.

In addition and of particular relevance is that only 11 Trusts (13%) stated they were aware of internationally agreed diagnostic criteria and only seven Trusts (8%) made mention of the RCP guidelines whilst not elucidating how these were delivered locally. Only one Trust mentioned BOAST guidelines. Of the 25 Trusts (29%) that described access to Pain services, 5 Trusts were via an indirect route by way of primary care. Nine Trusts (11%) had access to Psychology services, which were primarily within the pain team pathway. Twenty-seven Trusts (32%) described access to physiotherapy and occupational therapy services. In addition, two Trusts mentioned CRPS clinical champions.

Some themes that emerged in additional comments included: “Acute CRPS service is not commissioned”; “patient is referred back to GP for pain clinic referrals”; “care is provided on an individual need basis based on assessment” and “care pathway only applies to Rheumatology, not Orthopaedics”.

There were a few suggestions of a lack of evidence based care: one responder stated “acute care pathway includes 3 blocks” (not further specified) another stated “Use Budapest Criteria. Rapid access to pain team and pamidronate infusion protocol” but there was no mention of physio/occupational therapy or psychology input.

“One of our Consultants offers an unofficial CRPS service (not funded by Clinical Commissioning Group), with our Hand Therapy Team consisting of 2 Occupational Therapists, 2 Hand Physiotherapists and 1 Orthopaedic Hand Consultant. We offer upper limb blocks and examination under anaesthetic along with gabapentin or pregabalin therapy, with good results to date.”

Where care pathways were agreed (15 trusts), only three of these included referral or treatment timescales despite clear direction in the RCP guidelines regarding this. One care pathway was written in March 2017.

Discussion

Although The RCP guidelines have been in existence since, 2012 recommending early integrated MDT care for RPS with a view to reducing CRPS morbidity, this study found that English acute care NHS Trusts have generally not yet followed these recommendations. In addition most Trusts failed to mention BOA guidelines.

<table>
<thead>
<tr>
<th>Table 1. Analysis of pathway provision in NHS Trusts with relevant services (Category A: N = 84).</th>
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<tbody>
<tr>
<td>Category</td>
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<td>b</td>
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<td>A9</td>
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at all suggesting particularly poor awareness and compliance. Where there is a pathway agreed, it is rarely fully integrated and truly multidisciplinary; rather, a series of fragmented care pathways, to varying numbers of professionals existed (Table 2). Only seven (8%) respondents with relevant services included all core professionals (that is therapies, pain and psychology)18 in their acute service delivery for CRPS, i.e. were truly multidisciplinary. This is expanded in Table 2.

Possible reasons for the lack of care pathways
Several FOI responses from Trusts suggested that funding streams and service commissioning limitations may contribute to the lack of care pathways for acute CRPS. For example, FOI responses stated: “not commissioned”; “The Trust has no official pathway and the management of this condition is no longer an orthopaedic issue at the request of the CCG”; “the trust has no specific referral service for this. The acute pain service may see some of these and for chronic pain we ask the GP’s to refer as we have a contract with our CCG’s for referrals from GP’s only”; “Our commissioners do not fund an acute CRPS service nor do they provide a chronic pain service”. The apparent lack of awareness of national standards and recommendations suggest that dissemination is poor in acute care.

The lack of awareness of CRPS, the confusion of changing taxonomy over time and the variation in previous diagnostic criteria employed may have deterred clinicians from developing a specific integrated care pathway. At the authors’ workplace, it is certainly a condition that new staff consistently request as a topic for training.

Care pathways for other pain conditions may be present and CRPS patients may join these but there was no indication of this in the responses to this FOI request. The impact of having an integrated care pathway for acute CRPS is recognised as desirable but is as yet not quantified in terms of patient experience and cost benefit.

National commissioning guidance and service specifications for acute CRPS care could assist this particularly if supported with cost benefit and qualitative benefit analysis such as QALY (Quality Adjusted Life Years) analysis. Unfortunately, there is currently limited research data to quantify cost benefits or qualitative benefits of acute CRPS care pathways.

Most barriers to pathway development, such as a lack of time and pressure on staff, when explored are not true barriers as the patients are in the health system and are probably already on treatment. Conversely, whilst a passionate clinic lead and multi-disciplinary team (MDT) staff enthusiasm may facilitate the commitment to a pathway, lack of understanding, resulting in limited commitment across the MDT may inhibit it. Hence clear communication of the aims and benefits of a MDT pathway may expedite its development.

Limitations
This scoping project used FOI requests as a means to gain a snapshot insight into what acute Trusts perceive to be acute care pathways for CRPS. There were thirty-one Trusts who failed to reply which limits the generalisability. The enquiry was limited to England which further limits data analysis. It may be that some teams have not understood the request, or it was misdirected within Trusts. This may result in the response not being from the most appropriate clinician and therefore may be subject to misreporting (responding clinician is not known as responses come directly from the FOI department of each NHS Trust). Despite these limitations, there is a clear suggestion that integrated care pathways for acute CRPS are not routinely present.

Conclusions and recommendations
Guidelines formulated by BOA and RCP about acute CRPS management are not yet being followed in most of the relevant NHS Trusts in England.

NHS Trusts providing acute trauma orthopaedic, rheumatology and hand services should be made aware of national standards and recommendations regarding the assessment and management of CRPS. Additional methods of effective dissemination need to be explored.10,11

Local CRPS champions within relevant services would be a low cost solution to promoting cultural change and dissemination of best practice within acute NHS trusts.14,19

Local audits should include comparison against national standards to ensure the NHS is providing a

<table>
<thead>
<tr>
<th>N</th>
<th>Descriptor</th>
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<tbody>
<tr>
<td>12</td>
<td>Had access to both therapy &amp; pathway to pain team</td>
</tr>
<tr>
<td>2</td>
<td>Had access to both therapy &amp; psychology</td>
</tr>
<tr>
<td>7</td>
<td>Had access to therapy, pain team &amp; psychology</td>
</tr>
<tr>
<td>5</td>
<td>Had access to physiotherapy/OT only (not all stated rapid access)</td>
</tr>
<tr>
<td>6</td>
<td>Had a direct pathway to the Pain team only</td>
</tr>
<tr>
<td>9</td>
<td>Quoted national guidelines only</td>
</tr>
<tr>
<td>1</td>
<td>Quoted national guidelines and access to therapy</td>
</tr>
</tbody>
</table>

Table 2. Analysis of fragmented pathways in NHS Trusts with relevant services (Category A).
commensurate service that is not dependent on where a patient may live.

Local musculoskeletal services should be commissioned with CRPS care pathways in mind. Examples of service specifications and commissioning guidance should be formulated.

Further cost benefit and qualitative research is recommended to explore the barriers to developing these pathways and the potential benefits of an integrated care pathway.

Acknowledgements

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Declaration of Conflicting Interests

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Ethical approval

As this study does not involve human subjects and is only concerned with pathways, ethical approval was not required.

Contributorship

SG & FC worked on the first draft of the manuscript and collated the data. All authors reviewed & edited the manuscript and approved the final version of the manuscript.

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